
Book Review

Coping With the Death of a Brother or Sister. By Ruth Ann Ruiz. The Rosen Publishing Group, Inc., New York, 2001, 121 pp., \$25.25 list, \$18.95 online.

Coping With Hereditary Disease. By Marian B. Jacobs. The Rosen Publishing Group, Inc., New York, 1999, \$25.25 list, \$18.95 online.

Coping When a Brother or Sister Is Autistic. By Marsha Sarah Rosenberg. The Rosen Publishing Group, Inc., New York, 2001, 138 pp., \$23.95 list, \$17.95 online.

We are a genetic counselor and clinical social worker who collaborate in dealing with the psychosocial issues of individuals and families coping with hereditary cancer. In this regard, we are frequently seeking written materials that may be of use to those we see for counseling. Therefore, we were eager to review these books on hereditary disease, autism, and dealing with loss. The Rosen Group reports 50 years of publishing high-quality nonfiction guidance- and curriculum-based books for children and young adults. The volumes we review here are only three among dozens of Rosen Group books on diverse topics such as coping with an alcoholic parent, anxiety and panic attacks, compulsive eating, grieving and loss, melanoma, scoliosis, teen parenting, teen suicide, or Tourette syndrome.

Judging from the text and connecting links on the Rosen homepage, the marketing audience for the Rosen series is librarians, teachers, parents, and guidance counselors. It appears that adults are encouraged to purchase the Rosen books, and then give them to young people to read themselves. This is borne out by the text in the volumes, which addresses the young consumer directly with phrases such as “You don’t choose them; they are given to you . . . your brothers and sisters.”

We found the reading levels of all three books too high for much of their teen audience. All are described on the Rosen website as have a reading level of Grade 8 and an interest level of Grades 7–12. However, the level and style was uneven between the books and even within two of the books. In fact, on a commonly used readability scale, one section of the volume *Coping With Hereditary Disease* was assessed at Grade 12. The tone of the autism and genetics volumes widely misses the mark, and is often serious, or frightening, or preachy. There were no or few pictures, illustrations, cartoons, tables, or figures. The content was outdated

or misleading in some cases. On the other hand, each volume has commendable aspects. A few examples from each of the texts will illustrate some of these points.

We were most satisfied with the book *Coping With the Death of a Brother or Sister* by Ruth Ann Ruiz. This small text summarizes a wide range of helpful information in succinct, easy-to-read prose. The reading level, however, is still above that which is promised. Furthermore, the layout of the book does not seem inviting to readers. Its absence of graphics or photographs, densely spaced text, and serious tone combine to make it hard going for a young reader, who may already be having difficulty concentrating. Our impression is that this book, like the others, is better suited for middle-to-older teens. It is perhaps even more attractive to teachers and other adults, who can use it to quickly review the salient issues surrounding death and loss before offering counseling to their grieving students.

That said, there are many strengths to this book. The author has organized the material in a sensible fashion, starting with a chapter that describes the initial shock one feels when learning of the death of a sibling ("This Cannot Be Happening to Me"), through the intense emotions felt during the funeral, to the impact of the loss in the weeks and months that follow. She describes the different rituals that help families come to terms with a loss. Ruiz also differentiates the characteristic impacts of different causes of death, for example, from the extremes of long-term illness such as AIDS, to sudden death by murder. She considers how families change because of a death, and how young people may feel isolated and confused. Periodically, the author recommends seeking help from a professional, concluding with a chapter on organizations in the United States and Canada that are dedicated to helping those suffering from a loss.

Ruiz's tone is gentle. Throughout the small book, she encourages young people to accept their feelings, and to share their thoughts with others. Her explanation for the guilty feelings that often accompany a death of a loved one—that it is "better" to assign blame to ourselves, than to accept that our lives are out of our control—is insightful, sophisticated, and may help alleviate distress. Poignant first-person narratives, reportedly direct quotations from teenagers, are sprinkled liberally throughout the chapters. They serve to illustrate, and thereby give permission to accept, the wide variety of thoughts and feelings teenagers may experience in this difficult situation. This is valuable, as teenagers often feel ashamed to acknowledge reactions of this kind, including fears that one is going crazy, feelings of anger at the deceased, envy, guilt, or even relief.

The book also covers topics such as how it feels when friends are helpful, and how to handle hurtful remarks. It answers the question about whether one is still a "brother or a sister" when a sibling dies, physical reactions teens might have, signs of more serious distress, and constructive ways to deal with loss, including helping others. However, Ruiz's use of the term "replacement relationships" is problematic. Her underlying theme (with which one cannot quarrel) appears to be

that working with or helping others is healing. We would suggest that for future editions, she find an expression that does not imply that one can “replace” a loved one.

The author of *Coping With Hereditary Disease* is Marian Jacobs, PhD. We expected a lot from this volume, its title suggesting direct relevance to genetic counseling. However, Dr Jacobs mentions genetic counseling only once in a single paragraph pertaining to prenatal diagnosis. Another of our disappointments was to learn of the apparent lack of formal genetics expertise of the author and advisors cited in the Introduction and Acknowledgements. Her scientific accomplishments date from the 1960s in fields such as geology, oceanography, ecology, and petrochemicals. She mentioned in the text that she is a two-time cancer survivor, although she did not tie this into any formal expertise in the oncology field.

The content of this volume turns out to be simplistic and outdated, much as might have been written in the 1970s. The style is factual, with scant information on exactly how one is expected to cope, except through general exhortations toward screening and prevention through healthy lifestyle, two messages hardly embraced by young adults.

The book's Introduction starts nicely with a discussion of individual variation and uses analogies such as the uniqueness of snowflakes to illustrate that “no one in the world has genes exactly like yours.” However, the author explains the “medical family tree” without ever introducing the term pedigree. Chapter One covers Mendel's peas, cells, inheritance, genes, and environment. The explanation of eye color allows only for brown and blue. The next chapter on types of hereditary diseases starts with the story of Olympian Flo Hyman, who won a silver medal in 1984 and then died in 1986 of an aortic aneurysm secondary to Marfan syndrome. This could be a pretty terrifying story for a teenage reader, especially an athletic one. This sort of emotionally wrenching illustration is repeated again with Tay Sachs disease, in which the author illustrates how a recessive disease may cause a baby who initially looks normal and healthy to deteriorate and then die horribly. At several points it was emphasized that there is no cure for many genetic conditions such as Tay Sachs, sickle cell anemia, and cystic fibrosis. While that may be technically true, the quality of life and life expectancy for people with genetic conditions certainly have undergone tremendous improvements over the last few decades. These advances and any sense of hope for persons with genetic disorders are conspicuously absent.

Another chapter covers ethnic origins, natural selection, and evolution as ways of explaining differences in frequencies of different conditions in different ethnic/racial groups. Again, many of the facts and arguments were of older vintage and did not include any of the newer molecular evidence. Nor did it include any comparative genomics, which might have proven to be very interesting to young adults.

The remaining chapters deal with genetic–environmental risk factors and understanding of chronic conditions such as diabetes, heart disease, cancer, alcoholism, and aging. There was not enough information for someone with a true interest in the topic and too much for the casual reader. For example, no chapter presented the detailed data and analysis of a sib-pair study to illustrate the evidence for a hereditary contribution to diabetes.

The most valuable chapter was the one on exploring one's family medical tree. The types of information one could gather and places to look for them are mentioned. A pedigree finally appears, although it is not labeled as such. The inclusion of positive as well as deleterious family characteristics was a bright touch. The final chapter on genetics for the new millennium mentions the Human Genome Project (sequence not completed at time of publication of this text), bioinformatics, and genetic privacy, all timely issues, but none covered with authority or clarity.

Coping When a Brother or Sister Is Autistic was an improvement over the volume on hereditary diseases. The author is a mother of two children, elementary educator and behavioral specialist for children diagnosed with autism. In the author's self-description, Ms Rosenberg states that she "seeks to help the siblings of people diagnosed with autism realize that they are not alone in the joys and challenges of growing up with a specially abled brother or sister." Again, although this is a noble cause, it is not realized in this volume, which reads more like a primer for graduate students.

We found that we learned a considerable amount from this text. However, we would argue that the reading level was too advanced for a teen or young adult, filled with highly technical terms that would challenge anyone not an autism specialist. The chapter on the "triad of impairments" discussed communication terms such as "pragmatics" and "prosody." While these were defined in the text, they were not included in the brief and haphazard glossary. Further, the descriptions of people with autism include formally correct but potentially disparaging language such as "Many individuals with autism have a fixed or unbending cognitive style."

Other chapters focus on problems related to diagnosis, treatment, and issues in adulthood for autistic individuals. One chapter of particular interest dealt with disorders related to autism. This covered Rett, Landau-Kleffner, Angelman, Fragile X, Prader-Willi, hyperlexia, Williams, and Asperger's syndromes. Unfortunately, the only one of these disorders described as "genetic" is Williams syndrome and the basis for the condition is not discussed.

The last few chapters change direction from the educational early chapters to more counseling- and advocacy-focused approaches. The chapter on "the sibling experience" talks about feelings and challenges often associated with being a teen with an autistic sibling. The "Helping Yourself" chapter covers education, peer support, and "sibshops," opportunities provided by an organization called "Sibling Support Project" run by Children's Hospital in Seattle to facilitate siblings of autistic individuals obtaining peer support in fun, recreational settings. Other

family resources are listed in the final section, "Where to go for help." The bottom line is that genetic counselors with an urge to write should contact the Rosen Group.

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